

SPINAL COURIER

The spinal cord disability information source for Arkansans since 1989

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Reaching Beyond Barriers

If you have never come to the Arkansas Spinal Cord Commission's conference, this is a good year to start—if you are a "regular" you will find this one of the best!

Reaching Beyond Barriers will be held Friday, May 21, 2004, at the C. A. Vines 4-H Center in west Little Rock. This year's conference has sessions to meet a variety of interests.

Keynote speaker Dr. Gaynell Colburn will provide a rousing start. Dr. Colburn, a Baltimore, Maryland native, was a teenage track athlete when she sustained her spinal cord injury in a car crash.

In her words, she "never stopped running," and since that time she has earned a medical degree and a Ph.D., done consulting for the Department of Defense, established a mentoring program through her own foundation and played the drums for Stevie Wonder! In 1998

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Dr. Gaynell Colburn of Baltimore will be the keynote speaker on May 21.

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Time to Sign Up for Camp!

Spring has arrived, and that means it is time to get ready for Spina Bifida Camp! Each year, the Arkansas Spinal Cord Commission, in cooperation with Med Camps of Arkansas and Camp Aldersgate, sponsors a weeklong camp session for children between the ages of 6 and 16 at Camp Aldersgate. This year's camp will be held from June 27 through July 2, 2004.

There is no charge to the family for this week of camp. However, each family is responsible for transporting their child to and from Camp Aldersgate.

For those of you unfamiliar with the camp, Camp Aldersgate is located in a quiet, rustic area in west Little Rock near Baptist Health Medical Center. And, as stated in the Camp's brochure: "The Med Camps program provides weeklong traditional residential camping experiences for children with specific medical and/or physical challenges....The activities increase the campers' self esteem by creating opportunities to meet personal challenges. Campers are able to learn from others who have similar conditions and experiences by living in a group environment. Participation in personal hygiene and housekeeping chores encourages campers' responsibility and independence."

Traditional camping activities such as nature hikes, outdoor cooking, arts and crafts, swimming and fishing are featured. Other activities include an accessible adventure/challenge ropes course, hand and/or foot driven catamarans,

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SPINAL COURIER

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With Thanks

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ASCC accepts tax-deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Oops!

Dear Editor:

Your article, *Higher Education Scholarships*, in the last issue of the *Spinal Courier* left out the letter "r" in the e-mail contact address for the Spina Bifida Association of Arkansas. The correct address is:

sigmondr@sbcglobal.net. I can be contacted there for information and applications or call me at **501-978-7222**.

Vickie Rucker Spina Bifida Association of AR

From the Director

It is spring—and all thoughts at the Spinal Cord Commission turn to 'conference.' Our educational conferences, the statewide conferences in even years and regional miniconferences in odd years, are some of my favorite things we do here at the Commission. It is always good to see old friends and new, learn about the latest technology and treatment and hear how things are done in other parts of the Country.

The events are great fun, but the preparation—well that is another story! It takes involvement by everyone on the Commission staff, over a six to nine month period to carry out a conference. Everyone doesn't work on it every day, but every day something gets done. Just when we think we have it down to a science, someone comes up with a new idea or a new problem comes up!

I hope you will come to the conference this year, not just because we've worked hard to make it happen, but because everyone can learn something new there. We'll have wheelchair and other equipment suppliers coming from all over the Country—you will see equipment that is 'cutting edge.'

The same for the educational sessions—we really have experts. If you are a caregiver or family member looking for support, you're trying to manage chronic pain, you are a Medicare recipient and wonder if the new drug program will help you or you want to buy your own house on a fixed income—we've got a session for you! And those aren't the half of it! There's also a free lunch and wheelchair drawing!

You will get a brochure in the mail soon, but consider this *your personal invitation* to the conference. My goal is to see 50 new faces at the conference this year. So, if you are already planning to come, bring a friend. If you haven't come before, make this your first.

I look forward to seeing you there!

Cheryl L. Vines

used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788** / **800-459-**

1517 (voice) / **501-296-1794** (TDD), or send your donation to:

AR Spinal Cord Commission 1501 N. University, Suite 470 Little Rock, AR 72207

Jake Bennett — Quail Man of Judsonia

Jake Bennett could be considered "the Quail Man of Judsonia." Jake has been involved with raising quail for the past nine years. However, it did take him awhile to get into the quail business.

Just over twenty years ago, Jake worked as a lineman for AP&L and farmed over 2,000 acres with his father. He had just completed building a 40 by 60 foot tractor shed when he was diagnosed with Guillain-Barré Syndrome. His life then took a different direction from what he had expected.

One Sunday while at church, Jake was touched by a scripture reading that mentioned quail. A short time later, while visiting a friend who was selling out of the quail raising business, Jake became interested. He had this big tractor shed sitting on his property. Surely a few quail might fit into that shed!

Jake's cousin purchased ten hens and five roosters for him. His



With a little help from his family and friends, Jake Bennett has been in the business of raising quail for the past nine years on his farm in Judsonia, AR.

many friends and former coworkers from AP&L came by and helped make the tractor shed wheelchair accessible. Another friend helped build cages that would accommodate Jake's functional abilities.

This past year he raised and sold about 1,200 quail to local individ-

uals and some hunting clubs. He keeps about 85 hens and half as many roosters.

Jake laughs about the fact that the hardest part of raising quail for him is when they get out of their cages—it requires a lot of effort by Jake to catch them!

ASCC Conference

Continued from page 1

she was the Essence award winner. Dr. Colburn's diverse, uplifting message will challenge you to reach beyond barriers.

Following her presentation will be sessions on a variety of topics, including an overview of the new programs and services for people with spinal cord injuries in the J. T. Stephens Spine Center at UAMS by Dr. T. Glenn Pait.

Other topics you won't want to miss include expert speakers from around the state and nation discussing topics such as: an update on the new Medicare Prescription Program, buying your own home, recreation, employment, stress management, SCI mobility programs, medications, personal care programs and two workshop sessions designed to meet many requests, *Medical Management of Pain After SCI* and *Caring for the Caregiver*.

In addition, the conference Exhibit Hall is guaranteed to have the largest demonstration of assistive technology in Arkansas this year! You will see all the chairs and cushions and other equipment you have read about and some things that you have not. Finally, we will be giving away a Quickie manual wheelchair at the end of the day, as well as other great door prizes.

Whether you are a person with a spinal cord disability, family member or health care professional, you will find something of interest—the only problem will be trying to see it all in one day!

You will be getting a conference brochure in the mail this month, or you can visit our website at www.spinalcord.ar.gov for a copy. For more information call 296-1788 or 800-459-1517.

Reach beyond your barriers, mark your calendar and find a way to be there!

We want to thank our conference sponsors:

A & D Healthcare LLC
Baptist Health Rehab Institute
Independence Technologies
J. T. Stephens Spine Center
at UAMS
Motion Concepts
Pride Mobility
Spina Bifida Association of AR
Sunrise Medical / Quickie
TiLite Wheelchairs

SPINAL COURIER — 3

Common Medications Used in SCI Medicine Part Two - Bladder

By Tom Kiser, M.D., ASCC Medical Director

Bladder medications are often needed to maintain continence and prevent future damage to the bladder and kidney in individuals with spinal cord injury. In this article I want to discuss the different medications used for bladder management, why they are used and the side effects that can affect you if you take these medications.

Antispasmodics

Bladder spasms can be useful in stimulating the bladder to empty, but if you are unable to wear a condom catheter to catch the urine, or if the bladder sphincter shuts when your bladder spasms (causing high pressures to develop in your bladder and putting your kidneys in danger of damage), a medication to "paralyze" the bladder can be helpful. There are several medications on the market to paralyze the bladder, but the two that are used the most often are oxybutynin (Ditropan) and tolterodine (Detrol). Both medications work well. The side effects are dry mouth and constipation.

Oxybutynin and tolterodine can be given in the normal short acting formulation or as an extended release tablet or capsule (Ditropan XL or Detrol LA) which eliminate the peak effect of medication and decrease the side effects. Ditropan XL has a hard shell and can be found in your stools because it is not absorbed in the gut. The remaining shell for Ditropan XL is normal and does not mean the medication is not working (Detrol LA is fully absorbed by the gut).

The normal dose of oxybutynin is 10 to 20 mg a day. The normal tolterodine dosage is 2 to 4 mg a day.

As the dose goes up, however, the side effects also increase.

A new product on the market is an oxybutynin patch called Oxytrol. It has 3.9 mg per day in the patch and is changed two times a week. If you require a high dosage of oxybutynin the patch probably will not be enough for you, but if you take a low dose it may be of benefit. The side effect of dry mouth is usually managed by chewing gum or sucking on hard candy. The side effect of constipation can be handled with bowel medication, which I will discuss in a later article.

Alpha Blockers

The bladder sphincter can often cause problems by being spasmodic when your bladder is trying to empty, resulting in increased bladder pressure and autonomic dysreflexia (an odd feeling, headache, increased blood pressure and/or sweating). It can also interfere with catheterization.

If you desire to make any changes to your medication, discuss it first with your doctor to ensure it does not interact with your other medication.

Since the sphincter is supplied by nerves which are sensitive to what is called alpha stimulation, an alpha blocker, which is medication used to lower blood pressure, can be helpful to weaken the bladder sphincter. Doxazosin (Cardura), prazosin (Minipress) or terazosin (Hytrin) are three blood pressure medications which can be helpful. But, you need to watch out for lightheadedness due to lower blood pressure when you first sit up or



Tom Kiser, M.D., ASCC Medical Director

get up in your wheelchair in the morning. Another medication designed specifically to provide alpha blockade with minimal effect on blood pressure is tamsulosin (Flomax). I have found these medications to be very helpful in individuals who use a condom catheter but have problems with the side effects of autonomic dysreflexia or are not emptying well.

Alpha Agonists

If you have the opposite problem and your bladder often leaks whenever you try to transfer, cough or sneeze, you want to increase the bladder sphincter tone. To tighten the sphincter we often use what is called an alpha agonist. A medication that is cheap and is often

successful is Sudafed at a dose of 30 to 60 mg every four to six hours. Another medication is imipramine (Tofranil), which is an antidepressant that causes the bladder to relax and the internal sphincter to tighten. It can be used at a dose of 25 to 50 mg two

times a day. The main side effects of imipramine are dry mouth, blurred vision, drowsiness and constipation.

Remember, if you desire to make any changes to your medication, discuss it first with your doctor to ensure it does not interact with your other medication.

Next quarter, I will take up the discussion of pain medication.

Improve Your Future!

Have you ever thought of going back to school? Do you want to get your degree but just don't know how you can do it with all the transportation issues?

Why not try getting a degree online! Today, thousands of people are returning to college just by turning on their computers. Many universities and colleges now offer online classes as either individual classes or an entire program can be achieved without leaving your home

University of Arkansas at Little Rock (UALR) has an Off-Campus Program that offers web-based courses and an online Master of Arts in Rehabilitation Counseling. University of Phoenix is a well known online university offering degree programs in many fields, from bachelors to doctorate levels. Beware of phony degrees! Some online programs are not legitimate (such as those that offer degrees in just two weeks). You should thoroughly check out any school you are considering attending online to make sure they are accredited. Potential employers respect and recognize

accredited online degrees from a top college or university.

Several web sites you might want to visit to learn about accredited online degrees include:

www.theonlinedegree.com www.elearners.com www.schoolguideusa.com www.career-colleges.org If online education is not your preference, you might choose off-campus programs (such as UALR's, as mentioned earlier). The off-campus programs, which are offered by many colleges and universities, are designed to make a college education possible for those students whose commitments (such as work or family) or location make normal oncampus attendance difficult.

These off-campus programs often include television, interim and weekend courses. Check with the school of your choice to see what options they offer in off-campus education.

So what are you waiting for? Improve *your* future through available educational opportunities!

Thinking of Forming a Support Group?

ASCC has been actively working with St. Vincent Rehabilitation Hospital and Baptist Health Rehabilitation Institute in the development of spinal cord injury (SCI) support groups. Larry Wilson from the White County SCI Support Group has been very helpful with these two groups.

Some of the things we have learned throughout the past year are listed below. We hope this information is helpful for anyone in the process of starting up a support group.

Critical Components of a Support Group

- The group is a shared responsibility among all participants.
- The meeting place must be accessible and easy to find.
- Ample parking is close to the building of the meeting.

- The meeting is consistently at the same time and location.
- The group meets at regular intervals—preferably at least once per month.
- The meeting room is pleasant to be in and provides ample space for participants.
- The meeting room is set up in advance.
- The group acknowledges and welcomes new members.
- The serving of food encourages attendance.
- Participants have a voice and are acknowledged for their contributions to the group.
- The "developers" of a group make a commitment to maintain ongoing meetings for a minimum of one year.

Listed below are the meeting times of these SCI Support Groups:

St. Vincent Rehabilitation Hospital SCI Support Group meets the **third Thursday of each month** at **11:30 a.m.** Lunch is served. An invited speaker covers a topic of relevant information. Please contact Judith at **501-683-1124**.

Baptist Health Rehabilitation Institute SCI Support Group meets quarterly at 11:30 a.m. The next meeting is scheduled for June 4, 2004, and lunch will be served. For more information, please contact Judith.

The White County SCI Support Group meets the **first Tuesday of each month** at **10:30 a.m.** Contact Larry
Wilson at **501-724-3504** for more information.

SPINAL COURIER — 5

Up Close and Personal: Evelyn Wainwright

This is the second in a series of articles profiling the ASCC Case Managers.



Twenty-six years ago Evelyn Wainwright graduated from Southern Arkansas University and immediately began her career in state government. In 1989, Evelyn's experience with the state led her to the doors of the Commission's Magnolia office. Besides her familiarity with service provision, Evelyn's lifelong residency in South Arkansas was a definite asset in assuming the role of ASCC Case Manager. Currently her responsibilities include monitoring 135 clients in seven Southeast Arkansas counties.

As an ASCC Case Manager, Evelyn has used her counseling skills to assist many clients and their families in coping with a spinal cord disability. Over the years she has learned that often one of the most important skills of a Case Manager is effective listening. She always encourages those individuals on her caseload to not be afraid to ask for help. According to Client Services Administrator Patti Rogers, "Evelyn's ability to effectively listen to her clients has enabled her to become an excellent problem solver. Listening to what clients have to say plays an important role in finding solutions to problems and needs. If there is a solution, Evelyn will find it."

As an active member of her sorority, Delta Sigma Theta, Evelyn is involved in numerous community services, touching the lives of many individuals in her area. She can be found serving up steaming hot meals for the needy and homeless at the "Stew Pot" in Magnolia twice a month in the evening.

We can easily see Evelyn's persistence and desire to help others reflected in both her professional and personal pursuits.

PROFILE:

Date And Place Of Birth: July 19, 1954, in Strong, AR

The Animal I Most Identify With Is: Tigress

I Absolutely Will Not Eat: Oysters

If I Did Not Live In Magnolia, I Would Want To Be: In

Florida

My Favorite Movie Is: The Pelican Brief

My Favorite TV Show Is: 1-800-MISSING

My Favorite Song Is: Any song by Luther Vandross

The Guests At My Fantasy Dinner Party Would Be: Oprah, to teach me the fine art of becoming independently wealthy and how to share it with others; Whoopi Goldberg, to share the joy of laughter; and Maya Angelou, to give me wisdom and knowledge on living a good life

I Am Most Comfortable With People Who Have: Minds that are open to change and comfortable with who they are

My Favorite Pastime Is: Reading

My Pet Peeve Is: Being picked up late, especially when you have borrowed my car

The Best Advice I Ever Received Was: From my mother, "Educate yourself, knowledge is something no one can ever take from you"

My Favorite Saying Is: Life is hard

I Knew I Was Grown Up When: My parents refused to pay my bills after I got my first job

The Latest Book I've Read Is: What Becomes of the Broken Heart by E. Lynn Harris

The One Thing I Always Wanted To Do But Have Never Had The Chance Was: Go to Law School

My New Hobby Is: Learning to swim

One Word To Sum Me Up: Dependable

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Spring Means Corvette Show

The Corvette Club of Central Arkansas has played an important role in the lives of people with spina bifida in Arkansas for nearly 20 years. The Club supports the activities of the Spina Bifida Association of Arkansas (SBAA), assisting them in conducting events such as the annual Christmas party, family support, scholarships, educational activities, gifts for new babies and other programs and services. The primary source of the support is the Club's annual Corvette Show.

This year's show will be held at the Old Train Station in Hot Springs, Arkansas on **April 24**, **2004**. Corvette owners from all over the Midwest and South bring their cars to show. A tradition at the Hot Springs Show is the barbecue dinner prepared by SBAA board member Gary Crockett of Conway. Some corvette owners say they come to the show just for the barbecue!

If you would like to support the Spina Bifida Association, come out to the show (admission is a donation). If you would like to help, call the Spina Bifida Association of Arkansas at 501-978-SBAA. Volunteers are needed to help with information booths and to take donations.

Think spring—think a bouquet of colorful corvettes!

Spina Bifida Camp

Continued from page 1

adapted archery, an actual tree house—and for older campers, scuba diving.

There is also a pool party, sundaes on Monday night and a Thursday night dance. Also, campers have the opportunity to join various clubs, such as SCUBA, Boatin' & Fishin', AC Xtreme, and a Clowns Club, just to name a few.

All of the cabins, health care center and activity buildings are airconditioned and fully accessible. A new multi-use activity center, The Commons, should be completed in time for the summer camps.

In addition, from the time camp starts on Sunday afternoon until camp ends on Friday morning, trained counselors, volunteers and Med Camps medical specialists supervise the campers.

This really is a time of growth and learning for all of the campers while they spend a week full of fun-filled activities. Applications and brochures were sent out in March.

We only have room for 45 campers, and acceptance will be based on a first-come, first-served basis—so be sure to send your application in as soon as possible!

If you have questions regarding camp, you can call Mary Jo Stanton at **501-296-1788** or toll-free **800-459-1517** or by e-mail at mjstanton@arspinalcord.com.

See you at Camp!

Ms. Wheelchair Arkansas Pageant

This year the Ms. Wheelchair Arkansas Pageant will be held **June 17-19** in Jonesboro at Arkansas State University's Fowler Center. This is not a beauty contest, rather the pageant focuses on the contestants' abilities and accomplishments since the onset of disability. Ms. Wheelchair Arkansas acts as a spokesperson representing people with disabilities and travels to different locations within the state, in addition to representing Arkansas at the national pageant.

The 2003-04 Ms. Wheelchair Arkansas is Michelle Grisham of Mountain Home. She is a single mother, full time college student at ASU Mountain Home and very active in her community. She also has a beautiful voice and loves to sing. In July, Michelle will represent Arkansas at the 2004 Ms. Wheelchair America Pageant in Richmond, Virginia.

All interested persons should contact Ida Esh't, Coordinator of the Pageant, for information and



Michelle Grisham of Mountain Home is the reigning Ms. Wheelchair Arkansas.

applications at **870-335-9002**, by e-mail at **idaesht@yahoo.com** or by mail at P.O. Box 484, State University, AR 72467.

The deadline for applications is **April 15**, so hurry and turn in yours!

SPINAL COURIER — 7

McCluer Education & Resource Center News

We have a great new book to loan in our resource library—the *Paralysis Resource Guide* by the Christopher and Dana Reeve Paralysis and Resource Center. This informative book contains all sorts of information regarding different agencies and web sites that offer information and support for those who have all kinds of spinal cord disability related conditions.

Also, if you have access to the Internet and want to talk with other persons with disabilities, check out these web sites:

• CareCure Community offers Internet forums, news and information on paralysis. You can reach this web site at http://www.sciwire.com

- *Dangerwood* is another Internet community who offers answers from those who have been there. See http://www.surviving paralysis.com
- Want some general information on all kinds of topics? Log into the *New Mobility* web site at http://www.newmobility.com

We are also offering a complementary copy of our video entitled, *Accessible Living*. This video tours homes of four clients of ASCC and features modifications, including overhead tracks, elevators and universal design. Get some great ideas for your own home! For a free copy while supplies last, call Judith at **501-296-1792**.

Ready to Go Fishing?

Lake Dardanelle now has a wheel-chair transfer platform constructed by the AR Game and Fish Commission. The platform sits on the side of the boat ramp at Spadra U.S. Army Corps of Engineers Park on the lake. Its height allows wheel-chair occupants an easy access point for trailer mounted party barges.

Those persons who do not have the use of their hands can also open the gates. There are three transfer handles located on each post for a hand held support, according to regional maintenance coordinator Jim Price. "All boats sit at different heights on their trailers. The platform allows any boat owner the ability to load a wheelchair occupant if desired," he said.

The park is located south of Clarksville on AR Highway 103 at the Spadra Use Area on Lake Dardanelle.

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